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*No one scans you and says 'You're alright now': The experience of embodied risk for young women living with a history of breast cancer*

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**Abstract**

The concept of 'embodied' risk has been used to understand the experience of being at risk of cancer, yet there has been less engagement of the concept in relation to those who have been diagnosed and treated for the disease. In this paper, I draw on young women's accounts of living with breast cancer with the aim of developing analyses of embodied risk and expanding our understanding of the concept. Twenty women diagnosed with breast cancer while they were aged 18-44 took part in semi-structured interviews in the UK, and I analysed these interview data using social constructionist grounded theory. The findings illustrate how a sense of risk from within the body shaped the young women's experiences and perceptions of their bodies, and how their body as risky was relational, becoming salient in interactions with others. I also explore new dimensions of embodied risk related to the age and social circumstances of the young women. Although the fear of cancer recurrence is well documented, this paper explores it as an embodied experience.

***Keywords: embodied risk; breast cancer; young women; age; risk; experience***

**Introduction**

Risk and its calculation have become pervasive facts of medical discourse and practice (Lupton, 2012). A major question for sociologists in the field of health is how this pervasiveness of risk shapes the everyday lives of individuals who encounter it. According to Hallowell (2006), 'the lived reality of risk should no longer be overlooked' (p.10). Despite

the attention given to the experience of breast cancer in the literature on illness experience, there has been relatively little engagement with the concept of risk, specifically embodied risk, after breast cancer. The threat and fear of recurrence is mentioned in most published studies, but there has not been a great attempt to understand how women experience this in their everyday lives in relation to their bodies, and how this shapes their self-perceptions. In order to contribute to understandings of this subject, I drew on the concept of ‘embodied risk’ (Kavanagh & Broom, 1998; Robertson, 2000) to explore young women’s experiences of life with a history of breast cancer.

### *Context*

There has been a shift in attention from the actual to the potential disease in medical discourse (Hayes, 1991, 1992; Lupton, 1995), of which one effect has been the convergence of experiences of being ‘at risk’ and being treated for disease (Aronowitz, 2009).

Increasingly, the bodies of interest to medicine are those which would previously have been considered healthy, rather than those which are currently sick or diseased (Lawton, 2003). In the case of breast cancer, women may opt to take action in the form of preventive surgery even if they do not currently have breast cancer. Rates of prophylactic mastectomy are increasing (Murphy, Milner, & O'Donoghue, 2013; Yao, Stewart, Winchester, & Winchester, 2010), and the group most likely to undergo this surgery are younger women. Sociologists have investigated the impact of these developments in the field of cancer (e.g. Hallowell, 2000). In particular, the impact of genetic counselling has been explored, and the findings of these studies highlighted the disruption to a person’s lifeworld of genetic risk results, and how a patient is ‘repositioned’ to a liminal state, located between ‘healthy’ and ‘ill’, no longer fitting simply into either category (Frank, 1995; Hockey & James, 2003; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Scott, Prior, Wood, & Gray, 2005).

Elsewhere I have reported the experience of liminality in young women with breast cancer, as they negotiated their status betwixt and between ‘healthy’ and ‘ill’ (Rees, 2017).

I use the concept of embodied risk in order to explicitly ‘bring the body in’ (Williams, 2006) to an understanding of the lives of those ‘beings-at-risk’ (Scott et al., 2005). In their research with women who had an abnormal cervical smear, Kavanagh and Broom (1998) identified that women experienced ‘embodied’ or ‘corporeal’ risk as a result. The authors argued that social scientists have focused on environmental or lifestyle risks, but embodied risk is a third type which individuals experience. In this third type, the risk is located not in external surroundings (environmental), or in the behaviours or decisions (lifestyle) of individuals, but rather within individuals’ own bodies (although it can also overlap and interact with environmental and lifestyle risk). After an abnormal smear result, women experienced their bodies as inherently risky, and the annual smear tests as acts of surveillance through which ‘the body [was] continually produced as a source of danger’ to the women (p.440). This resulted in a sense of alienation from the body, as it came to be seen as a threat and as unpredictable. Women who attend a breast health clinic for screening or information also experience embodied risk (Robertson, 2000), in particular those with a family history, who perceived their breasts to be ‘treacherous body parts’ (p.223), or ‘time bombs’ (p.225). Elsewhere, researchers have shown that women draw on their own biographical and experiential knowledge, as well as expert knowledge, when making sense of health risks such as family history or carrying genetic mutations for breast and ovarian cancer (Hallowell, Foster, Eeles, Ardern-Jones, & Watson, 2004; Hesse-Biber, 2014). These studies have illustrated the ways that embodied risk shapes a person’s understanding of their self, and a new self emerges as a result of this sense of being at risk, along with new ways of being in the world (Robertson 2000).

Largely missing from these developments of the concept of embodied risk are the accounts of those who have themselves been treated for cancer. My aim in this paper is to explore whether the concept of embodied risk is useful for understanding women's self-perceptions and experiences of their bodies *after* breast cancer treatment. By bringing their (embodied) accounts into the discussion, I shed further light on the way that being treated for a disease and perceiving oneself to be at a higher risk of a disease are converging in terms of how they are experienced.

## **Methodology**

In this article, I draw on data from a study conducted in the UK between 2011 and 2015 (Rees, 2015). An interpretive approach was taken, and the study was informed by social constructionist grounded theory (Charmaz, 2014). Charmaz's approach offers 'systematic, yet flexible, guidelines' well suited to the interpretivist paradigm, and a social constructionist theoretical position.

Twenty women participated in semi-structured qualitative interviews. The participants in this study were identified and accessed through a diverse group of support groups and gatekeeper organisations. The inclusion criteria were: women diagnosed with breast cancer while aged 18-44; diagnosis was at least 12 months previously and within the last 10 years. All participants had completed their initial treatment in the UK and were not currently receiving treatment for cancer other than long-term preventative treatment (such as Tamoxifen). None had suffered a recurrence with the exception of one participant who had been treated for two subsequent metastases, but was no longer receiving any form of treatment. Nine participants stated they had a family history of breast cancer (including two with a confirmed BRCA mutation). Table 2 contains demographic and treatment information about the participants. Three of the women had been pregnant at the time of their diagnosis (for a discussion of this see Rees and Young (2016)), all with their first and only child at the time of the interview.

*Table 1 – Sample characteristics*

<b><u>Characteristic</u></b>	<b><u>Number (Percentage of sample)</u></b>	<b><u>Range (Mean)</u></b>
<b>Age at diagnosis</b>		22-44 (33.8)
<b>18-24</b>	1 (5)	
<b>26-30</b>	6 (30)	
<b>31-35</b>	4 (20)	
<b>36-40</b>	4 (20)	
<b>41-44</b>	5 (25)	
<b>Age at interview</b>	-	26-53 (37)
<b>Time since diagnosis</b>	-	15 months–9 years (3.5 years)
<b>Ethnicity</b>		
<b>White</b>	17 (85)	
<b>Asian</b>	1 (5)	
<b>Black</b>	1 (5)	
<b>Dual heritage</b>	1 (5)	
<b>Sexual identity</b>		
<b>Undisclosed</b>	18 (90)	
<b>Lesbian</b>	2 (10)	
<b>Disability (before diagnosis)</b>	18 (90)	
<b>None</b>		
<b>Yes</b>	2 (10)	

Interviews were audio-recorded with participants' consent and were transcribed verbatim and entered into NVivo. Data analysis had three phases. Firstly, initial coding was conducted concurrently with data collection. In this phase, I stayed close to the data and summarised processes which were 'going on' in the data, using action language to code processes rather than topics or events.(Charmaz, 2014). This enabled the exploration of the processes which were evident in the data, rather than a set of topics. I also found it useful to code segments in the original words, enabling the women's own words to remain intact (Hesse-Biber, 2014).

After performing this initial coding, I undertook the second phase of coding, which involved sorting and synthesising initial codes and making decisions about which codes were the most useful, significant, and effective, in building an interpretation of the data. This process produced codes which were "more directed, selective, and conceptual" (Charmaz, 2006, p. 57). This was performed by collating all codes under their umbrella nodes, printing them off and manually going through them and noting similarities between, and connections within, nodes. It was in this phase that my coding work highlighted the salience of embodied risk for my participants. This was an exploratory study of young women's experiences of breast cancer and I did not originally set out to investigate embodied risk.

In the third phase, I again examined the data but with specific elements of my theoretical framework (comprised of embodiment, biographical disruption, survivorship, and gender and its intersections) in mind. For example, I focused particularly on the parts of the accounts in which women spoke about their bodies and embodied experience. Rather than imposing pre-existing categories on the women's accounts, this allowed a more focused and attentive analysis of the ways that the young women experienced and perceived their bodies. I created a new codebook on NVivo which was solely focused on embodiment. This phase of coding was similar to Charmaz's account of 'axial coding' (2006).

This process of analysis enabled the development of categories and subcategories, and an understanding of “the properties and dimensions of a category” (Charmaz, 2006, p. 60). It produced ‘theoretical codes’, described by (Glaser, 1978, p. 72) as “weaving the fractured story back together”. By comparing data across codes, developing the categories, and drawing links and comparisons between the categories and subcategories, relationships between categories emerged, and this created a broader picture of the young women’s lives (Hesse-Biber, 2014). Throughout this whole process, I aimed to remain open to alternative interpretations of the data and had continuous discussion with colleagues and supervisors which challenged me to justify my interpretations.

The Humanities and Social Sciences Research Ethics Committee at the University of Warwick approved the study.

## **Findings**

During the interviews and analysis, living with the fear of recurrence emerged as a significant theme in the young women’s accounts. This was not surprising as existing research has identified the importance of fears about recurrence (Adams et al., 2011; Allen, Savadatti, & Gurmankin Levy, 2009; Dunn & Steginga, 2000), but analysing this within the framework of embodiment highlighted how they experienced risk as inherent within their bodies, and that this profoundly shaped their experience and understanding of their bodies.

### ***Young women’s experiences and perceptions of embodied risk***

Living with a history of breast cancer for many of the young women involved living with risky breast tissue, either after a lumpectomy or in their unaffected breast. Women who had lumpectomies described changes to their breast tissue which occurred as a result of surgery, and these changes inhibited the young women’s ability to feel confident that they now knew how their breasts should feel.



*When I check for lumps, it feels completely different to how it used to feel because there's a lot of scar tissue I guess, and so the whole feel of the breast is completely different.* – Evelyn

*There's so much lumpy scar tissue that you can't recognise a good lump from a bad lump so it's like how am I meant to recognise it?* – Lyndsey

The young women were contending with their perception of their bodies as a source of danger and the profound anxiety which arose around the time of annual check-ups.

*It never feels like it's gone away, it never feels it, even though you know that lump isn't there anymore, it's always that y'know that fear that it's gonna come back. And they say to you about checking your breasts and things and you do it but you do it tentatively because you're bloody terrified of finding something else.* – Charlotte

On the other hand, Sarah checked herself almost obsessively.

*The last oncologist I saw um I said 'I check my breast every day' ...He goes 'That's a bit much, don't you think?' ...But I still sometimes tend to sit down and do this [feels for lump] with the other one and across the scar, can't help it.* – Sarah

Most of the women who talked about breast self-examination described performing it tentatively, like Charlotte above, and without confidence in their ability to find a new lump, particularly in breasts with lumpectomy scars and resulting scar tissue. The participants thus felt heavily reliant on biomedical knowledge to define them as being healthy or ill, as having cancer or not. This highlights that living through the experience of breast cancer may mean not only losing trust in one's own bodily knowledge, but also surrendering a level of autonomy of the body to medical professionals and conforming to medical regimens.

Paradoxically, at the end of their initial treatment, the young women were confronted with the

realisation that medical knowledge was limited in its ability to define them as cancer-free or not.

*No one scans you and says 'You're alright now'. – Lyndsey*

*'No evidence detected' they say at the minute. – Beverley*

The language used by many of the women illustrated that, despite receiving treatment which was considered successful, the young women continued to see cancer as hiding within their bodies.

*My cancer could still be there, like a tiny little cell that one day will explode. –*

Melanie

*There's an element in my head of worrying if it's still there lurking. – Dawn*

This contributed to a sense of distrust of their body which was perceived to be potentially harbouring an enemy within its 'secret unpredictable interior' (Crouch and McKenzie 2000:196). As a result, aches and pains which would otherwise have been seen as innocuous were experienced as potentially cancer.

*I think before if you had a headache you think 'Oh I've got a headache' or if your foot's hurting you think your foot's hurting, whereas now I tend to think 'Oh is that cancer? Has it come back?' – Sarah*

As has been previously noted (Klimmek & Wenzel, 2012), after cancer treatment, people enter into a stage of watchful waiting. This fundamentally shaped the young women's experiences and perceptions of their bodies after breast cancer. They did not fit neatly into the categories of 'healthy' or 'ill', 'cancer-free' or 'cancer patient'.

This was perhaps magnified for the young women because, at the time of their diagnosis, they had felt fit and well, and the diagnosis did not make sense with how they had felt in their bodies.

*I feel like I would be one of the last people to be diagnosed with breast cancer...I've always been like 'little Mel', how can cancer get into my little body? – Melanie*

*I wasn't sick, I was in the prime of my life, I was healthy, I was fit. – Sarah*

This can be understood as a 'dys-embodiment' experience (Williams 1996:23). In normal everyday life, individuals have a largely taken-for-granted experience with their body, but an event such as cancer can cause the body to become problematic, and an individual may become alienated from their body. They had felt well in their bodies: how could it have been that they were actually ill? The nature of breast cancer means that women often feel well apart from a breast lump when they are diagnosed. The diagnosis thus undermined the young women's trust in their bodily knowledge, and this left them wondering how they would know if they experienced a recurrence.

The combination of the loss of trust in bodily knowledge, the persistence of bodily reminders, and the limitations of medicine, resulted in a state in which the young women came to view their bodies as threatening; harbouring and hiding a potentially lethal cancer.

### ***Dimensions of embodied risk related to the women's age and life stage at diagnosis***

This perception of their bodies as inherently risky was related to their age and life stage at diagnosis. All of the young women interviewed had been pre-menopausal at diagnosis, and a large number of them were hormone receptor-positive. Eighteen of them were, as a result, receiving long-term hormonal treatment, such as Tamoxifen, as a preventative measure. Consequently, they viewed hormonal changes, such as the return to a pre-menopausal status, or becoming pregnant, as dangerous.

*If they're telling me they wanna suppress my ovaries because the tumour was fuelled by hormones, if my ovaries restart [after ovarian suppression treatment ends]...Does that mean that there's more hormones now flying around again? – Beverley*

*A few people offered to be a surrogate for us [but] I would have had to have all the hormones and my cancer was fed on hormones so why would I want to have more hormones put into me to potentially make it come back? – Kim*

For some women, the side-effects of the long-term hormonal treatment, and ovarian suppression, were sometimes viewed positively:

*It is your ovaries going to sleep that are making you ache...It doesn't get me down in the dumps 'cause I'm happy to be here...I think 'Well it's doing its job and I'm here'.*  
– Beverley

The side-effects were seen as evidence that the treatment was working, and therefore that they were less at risk of recurrence. For these women, reducing their risk meant preventing their bodies from returning to a pre-menopausal state, or from becoming pregnant. The implications of this for the women's life course are discussed elsewhere (Rees, 2017), but it is important to note that this also shaped how young women experienced and felt about their bodies after treatment. The circumstances of the women clearly had an impact; for women not planning to have any (more) children, menopause was constructed as a safe bodily state, whereas for those who were hoping to have (more) children, they continued to question and fear what could happen if their bodies were no longer menopausal.

Faith's account below demonstrates powerfully and poignantly the significance of age to young women's lives with embodied risk after breast cancer, as they looked ahead to the many decades during which cancer could recur.

*Everyone sort of like I know that's ever had cancer...If they don't die from it when they first get it, either it comes back or they end up getting a different type of cancer like however many years on...I kind of always said to myself 'Am I really gonna go sixty years without getting cancer again?' – Faith*

Three women in the study (Dawn, Vanisha, and Faith) had undergone contralateral prophylactic mastectomy (CPM). CPM is the removal of the breast which was not involved in their cancer, in order to reduce the risk of cancer developing in that breast. Another participant, Charlotte, was in the process of arranging her bilateral prophylactic surgery (BPM, removal of both breasts), and several more of the participants talked about having asked their consultants about their eligibility for BPM or CPM.

Research has found that young women are more likely to opt for CPM than older (Jones et al., 2009; King et al., 2009; Tuttle, Habermann, Grund, Morris, & Virnig, 2007; Yao et al., 2010). Charlotte and Tabitha's accounts demonstrate the relevance of the concept of embodied risk in understanding the young women's perspectives on preventative surgery:

*I did ask to have a double mastectomy and got told 'No that wasn't necessary'. So that's probably maybe once a week I have a look at good booby and I think 'I hope you don't let me down'. I don't want to go through that again. – Tabitha*

*Losing my breasts is a massive thing really and given a choice I would clearly not want to be doing it, but I can't spend, really I don't feel like I could spend the rest of my life looking over my shoulder and thinking 'Has the cancer come back?' –*

Charlotte

Charlotte was a wheelchair user, and the radical surgery had implications for her mobility, given her reliance on her arms to move around. Despite this, the idea of living every day with the threat of recurrence and her 'risky' breast tissue was a powerful motivator, especially in

the context of Charlotte's strong family history of cancer, and her confirmed BRCA mutation.

Many women are unable to access such surgery because they do not have a family history, an identified BRCA mutation, or enough money to have private treatment. Beverley felt frustrated with her inconclusive test for a BRCA mutation because it meant she could not get preventative surgery via the NHS. However, NHS rules allow a reconstruction and a reduction (to ensure breasts match in size) for women in Beverley's circumstances. As a result, she made the decision to have reconstruction, and her account revealed that her fear of recurrence was central to this decision.

*My surgeon has said he will take some of the tissue from this [unaffected] side to reduce it, so in my own head if it's smaller, if my boob's smaller, there's less risk...He can't take it off, but he'll reduce it for me. – Beverley*

Beverley's first choice was to have no breasts: a CPM with no reconstruction. Instead, she was forced to have reconstruction and reduction, which alleviated some of her sense of being at risk. This illustrates a tension between the action young women may wish to take to reduce their sense of embodied risk, and the socially organised regulation of women's bodies according to gender ideals (Pelters, 2014) amid constrained healthcare budgets.

### ***The body and risk in young women's interactions with others***

A significant point which many of the women wanted to emphasise to me during the interviews, was that breast cancer did not only affect them, but also those around them. Their accounts revealed that their perceived sense of risk of recurrence as located within their bodies was also experienced by others and within interactions with others.

*Just as I'm aware that I could get a recurrence, I imagine my sister is, and other people. – Vanisha*

Others around the women also reinforced their sense of being at risk by monitoring their bodies, or governing their participation in behaviours deemed as risky. For example, Gemma described her husband as being ‘*constantly on my back*’ about any aches or pains she had.

Evelyn said similarly:

*Every couple of weeks [partner] will say something like ‘Are you alright, have you checked yourself?’ or ‘You shouldn’t be eating that chocolate bar’ or something. –*

Evelyn

Evelyn went on to describe how the re-positioning of hormonal contraception and pregnancy as dangerous impacted on her sexual relationship with her partner.

*We had to swap to using condoms...I really miss that side of things...There’s one thing it has changed is that [partner] is absolutely terrified of getting me pregnant. –*

Evelyn

This sense of being at risk could be reinforced by health professionals. For example, Faith described how her health providers had ‘whipped out’ one of her ovaries unnecessarily during a (false) ovarian cancer scare.

*I asked about egg freezing but he [surgeon] was just like ‘Well would you want to keep eggs from a dodgy ovary?’ – Faith*

The young women’s bodies as risky were therefore experienced in interactions with others and impacted on the young women’s relationships. This was also mediated by the significance of hormones and the young women’s status as pre-menopausal at diagnosis.

### ***Absence of embodied risk***

Not every woman I interviewed seemed to be living with embodied risk, or at least risk seemed to be less prominent in some of the young women’s accounts. Mehnert, Berg,

Henrich, and Herschbach (2009) explored the frequency of fear of cancer recurrence in women with a history of breast cancer using quantitative measures, finding that it was higher among women who received chemotherapy. While the nature of my sample does not allow me to generalise, risk *was* less salient in the accounts of Olivia and Joanna, both of whom were told that chemotherapy was optional for them and who chose not to have it. I asked Olivia if she worried about recurrence and she said:

*No I don't. Um I guess yeah I've never regretted the decision not to have chemotherapy... I'm just gonna make sure that like I keep having regular mammograms...That's all I can do really.* – Olivia

It is possible that Olivia minimised the risk of recurrence to reconcile her decision not to have chemotherapy. Olivia made her decision in the light of having seen a close friend suffer through chemotherapy, supporting Hallowell's (2006) contention that seeing another person endure suffering forms part of the experiential knowledge which shapes people's responses to risks.

Joanna also chose not to have chemotherapy, in large part because she was concerned about its effect on her fertility and having children was extremely important to her. Joanna was also aware that the limits of medicine to define her as cancer-free would apply whether or not she had chemotherapy.

*You can't ever be given a 'you are all in the clear'...It's like 'Well we'll keep testing you for a certain period and then we'll probably leave it at that' but I don't know if they really mean they can then say you will never, or that you're completely clear of any possibility of it coming back.* – Joanna

In contrast, Catherine *did* have chemotherapy, but she was not very concerned about recurrence, instead placing great confidence in medical treatment and health professionals.



*I believe [consultant] when she says I'd be unlucky if it came back. – Catherine*

Catherine's mother had been treated for breast cancer a number of years previously, and had not experienced a recurrence, and she talked about how this had shaped her perceptions.

*My mum had breast cancer so my parents were quite sort of, well not relaxed about it, but they know that you can have treatment and get better, and also seeing someone do that and yeah be fine with it. – Catherine*

All of the young women drew on their biographical and experiential knowledge, as well as medical knowledge, in order to make sense of living with risk.

On the other hand, Evelyn opted not to have chemotherapy, but risk was a very strong theme in her account, and she had made dramatic changes to her lifestyle and diet in order to prevent recurrence.

*I feel responsible for trying to keep myself as well as possible but I don't know how to do that so I'm kind of taking in as much information as I can in the hope that if I try and do a bit of everything it'll help. – Evelyn*

Further research is required to investigate possible explanations for the differences between women who did and did not experience such a profound sense of embodied risk and why fear of recurrence is associated with the experience of chemotherapy.

## **Discussion**

In this paper I have sought to further develop the discussion around the concept of embodied risk, which has been given little explicit consideration in the literature since it was introduced. I have expanded understanding of the concept of embodied risk, by fleshing out dimensions of embodied risk related to the age and social circumstances of the women at diagnosis, and by exploring how the body at risk was experienced in interactions with others,

shaping and re-forming the women's relationships. Interactions with others, including health professionals reflected and informed the young women's perceptions of themselves as 'beings at risk' (Scott et al., 2005). I have also reinforced the convergence of the experiences of being at risk of cancer, and living with a history of cancer, as other authors have theorised (Aronowitz, 2009). This builds on Kavanagh and Broom's and Robertson's work on embodied risk, bringing the concept of embodied risk into our understanding of those living with a history of cancer.

Researchers examining a large dataset to explore patterns of cancer screening attendance in the UK found that women previously diagnosed with breast cancer were 22% *less* likely to attend a mammogram compared with their matched controls (Khan, Carpenter, Watson, & Rose, 2010). The authors excluded women who had had a double mastectomy so this could not explain the difference. Accounts from the women I interviewed indicated that this could be related to fear. Kavanagh and Broom (1998) argued that, through medical surveillance (cervical smears in the case of their study), the body is 'continually produced as a source of danger to the subject' (p.440). Avoiding a scan may be a way of avoiding the sense of embodied risk for women living with a history of breast cancer. On the other hand, the data showed that women had lost much of their trust in their bodily knowledge, a finding which echoes previous research (Lindwall & Bergbom, 2009; Thewes et al., 2005). Research with young people with cancer and other illnesses has found that, after diagnosis, the body becomes a threat, and illness generates feelings of distrust, betrayal, and confusion, towards the body, because it contradicts their experience of their bodies as young adults (Burles, 2010; Snöbohm, Friedrichsen, & Heiwe, 2010). This highlights a paradox in the embodied experience of living with a history of breast cancer: an individual may lose trust in their bodily knowledge and feel reliant on medicine to define them as 'patients' or not, and yet

they may avoid medical encounters because of the way these encounters reinforce their sense of embodied risk.

Although women in this study grappled with lifestyle and environmental risks, and some made changes such as exercising and trying to reduce their exposure to pollution, most focused on the source of risk within their own bodies. This produced a new way of being in the world in which women were fearful of their own bodies - focusing on these bodies as a source of risk, as opposed to various external sources. The scientific consensus is that pregnancy after breast cancer does not impact on the breast cancer mortality rate (Azim et al., 2011), but women are advised not to become pregnant in the first two years after treatment because this is the period during which most recurrences occur (French, Brennan, Boyages, Houssami, & Kirk). Still, pregnancy and a pre-menopausal state took on new and dangerous meanings for the young women. In addition to their experiences of liminality being 'betwixt and between' the states of healthy and ill (Rees, 2017), a new subjectivity emerged in which they were produced as 'beings-at-risk' (Scott et al), and this informed their experiences of their bodies and their interactions with others. Further research drawing on theories of embodiment could explore how young women negotiate the challenges of regained fertility in their everyday lives, and how this informs their perceptions of their bodies.

Managing the risk of recurrence for the young women involved managing their bodies, and can be seen as an 'embodied enterprise' (Robertson 2000:230). Given the women's accounts, it should not be surprising that many young women opt for or seek CPM and other preventative surgeries (Jones et al., 2009; King et al., 2009; Tuttle et al., 2007; Yao et al., 2010). It seems that the risk of recurrence, for many women, trumped the benefits of keeping both of their breasts. Previous research has identified how genetic counselling for risk of breast and gynaecological cancers and the discourse around risk may constrain women's choices because of a sense of moral obligation to 'do something' such as have prophylactic

surgery, make lifestyle changes, or even avoid reproduction (Hallowell, 2001; Hesse-Biber & An, 2016; Mozersky; Rowley, 2007).

However, despite having had CPM, Vanisha, Faith, and Dawn all still lived with the fear that they would experience cancer elsewhere in their bodies. The sense of a risk was therefore not straightforwardly overcome through CPM. Indeed, CPM cannot provide a complete elimination of risk of breast cancer since it is possible that cancer cells can remain or develop in tissue in the chest wall (Lloyd et al., 2000). Other research has illustrated how, in addition to its failure to eliminate a sense of embodied risk, strategies to manage risk of cancer such as BPM have implications for a woman's gendered self-identity (Hallowell, 2000; Pelters, 2014).

I have touched on the ways that the sense of embodied risk might depend on whether a woman has undergone chemotherapy, but further research is needed in this area. It might be that being told that chemotherapy was required increased the young women's perceptions of cancer having spread further into the body, and therefore potentially remained, lurking. Being told that chemotherapy was optional (as in Joanna and Olivia's case) may have made the women feel more secure that their cancer had not spread and that they would not experience recurrence, although Catherine and Evelyn's accounts challenge this explanation. The suffering involved in the experience of chemotherapy may also have increased the women's sense of vulnerability in their bodies, as well as increasing the fear of recurrence which might result in another experience with chemotherapy, something which they desperately wanted to avoid. It also appears that the women drew on experiential knowledge of others' experiences of cancer to make sense of their own embodied risk. Any such further research on this topic should also employ intersectionality as an analytical tool, examining the ways that perspectives of marginalised people may shape their understanding of embodied risk (Olofsson et al., 2014).

## Conclusions

This study found that young women living with a history of breast cancer experienced embodied risk, and that this was related to their age at diagnosis. This exploration of age and embodied risk extends current knowledge about the experiences of young women living beyond breast cancer, and also about how individuals understand and experience risk. It prompts questions about why risk was more prominent in some women's accounts than others, and how to alleviate it, opening up avenues for further exploration. The fear of recurrence is well documented for those living beyond cancer, and through bringing in the concept of embodied risk I have built on previous research, exploring how it is experienced through the body and produces an altered way of being in the world.

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